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FAMILY CAREGIVERS OF HOME-BASED CLIENTS WITH ADVANCED CANCER: NEEDS AND PREFERENCES

By

Jo-Anne Dawn Pollard ©

A thesis submitted to Faculty of Graduate Studies and Research

in partial fulfillment of the requirements for the

Degree of Master of Nursing

Faculty of Nursing

Edmonton, Alberta

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Jo-Anne Pollard

Jo-Anne D. Pollard
P. O. Box 364
Thorhild, Alberta
T5A 3J0

Date Sept. 29/98

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled **Family Caregivers of Home-based Clients with Advanced Cancer: Needs and Preferences** submitted by **Jo-Anne Dawn Pollard** in partial fulfillment of the requirements for the degree of **Master of Nursing**.

J. Ross Kerr, RN, PhD Supervisor

P. Koop, RN, PhD Committee Member

M. Haughey, PhD Committee Member

Date September 22, 1998

Abstract

This descriptive pilot study focused on the needs, demographic characteristics and depression indicators of ten home-based family caregivers of persons with advanced cancer. Caregivers were asked to identify their needs and to rank them according to importance and satisfaction. Respondents were also asked who was meeting each need for them and who they would prefer to meet the need. Data were analyzed to determine the most important and satisfied needs and to determine which needs were being met and which would preferentially be met by informal support persons or by the formal support system.

The results of this study suggest that family caregivers of home-based cancer clients are resourceful in having their needs met. Their expectations of themselves are high. They want their formal support system to provide information and to help care for the client and their informal support system to help meet personal, spiritual, psychological and emotional needs.

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"And it is He who will supply all your needs from His riches in glory because of what Christ Jesus has done for us."

(Philippians 4:19. The Living Bible, 1971. Tyndale House Publishers: Wheaton, Illinois).

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Chapter One

Introduction

Background

Prior to the outset of the twentieth century in North America, if a person became ill or injured, they were mainly cared for in the home (Baumgart, 1992). This was because the majority of people lived in rural settings and usually had little access to formal health care and because the widespread growth of hospitals had yet to occur. In fact, the people were fortunate if they even had a physician in the vicinity. It was more common for "lay healers" (Larson & George, 1992) in the community who had knowledge of herbs and treatments gained through experience or lore (Colliere, 1986), to fill the vacant role of the physician. Regardless of the type of training, though, medical assistance was provided in the home.

Not surprisingly, lay healers (Larson & George, 1992) were primarily women. Even in the home, it was the woman's responsibility to care for anyone who was ill. It has commonly been the woman's role to care for the ill. Throughout the years, women have been socialized to believe their primary roles were those of homemaker and nurturer. Although women today generally work outside the home and are therefore less available for informal caregiving, they are still expected to maintain the caregiving role.

Toward the close of the nineteenth and into the twentieth century (Baumgart, 1992), the location of health care moved from the family home and into hospitals. There were

a number of reasons that this change occurred. The increase in industry and technology, focused in larger urban areas, resulted in the relocation of many people from the country into cities. In this new location, people didn't have the large informal social network that they relied on for health care in their previous rural settings. Also, life in the urban centres was crowded and difficult. Often the women who used to care for people in the homes were now out working themselves. Formal health care, including physicians, nurses and hospitals, was convenient and much easier to access. The rapid strides made in scientific knowledge and the greater availability of medications, treatments and diagnostic tests made the survival rate from illness and injury increase dramatically. Eventually, with a lower value being placed on care at home, the family was forced to defer to what was considered to be much superior health care in the hospital by those who had the new, specialized knowledge (Pepin, 1992).

Although forced to abandon its role as primary caregiver, the family continued to provide emotional support for its ill loved ones. As Pepin (1992) suggests, this support emphasized "the compassion, the presence, the comfort and sometimes the most intimate care" (p. 128) for the patient. The value of this emotional support in patient recovery is increasingly being recognized. Currently, family members are actively encouraged to visit their loved ones and to even stay with them on a continuous basis if desired, particularly when the patient is critically ill (Hull, 1989).

The current trend in health care provision is, again, moving back into the home. This shift from hospital-based to community-based care has occurred for several

reasons, both personal and economic. Many patients want to be at home with their loved ones and in familiar surroundings (Ferrell & Schneider, 1988), and many family caregivers are happy to care for the patient at home (Ferrell, Johnston Taylor, Grant, Fowler & Corbisiero, 1993). It is also a widely-held belief that patient care in the home is less expensive than that in the hospital. In times of decreasing health care funding, this has become an important consideration. However, this assumption of lower costs for home care over hospital care is predicated upon the willingness of families to provide a good deal of the home care themselves (Beck-Friis, Norberg & Strang, 1991; Stommel, Given & Given, 1993). As a result of these personal and economic reasons, care is being shifted to the home, and as much care as possible is being provided by the family.

In their new role, not only are family caregivers continuing to provide the important emotional support, but they are also expected to take on the often complex physical care that patients were receiving in the hospital (Haylock, 1993). Some of the new roles require the acquisition of scientific and technical knowledge previously considered the purview of the formal health care system. Examples of the technical care being undertaken in the home with advanced cancer patients are pump infusions for medications (Bruera, 1990), and hypodermoclysis (Bloch & Brown, 1990) to maintain hydration when the patient is unable to drink fluids in sufficient quantities.

Families of cancer patients may be unprepared to assume the caregiver role despite their willingness to do so (Feldstein & Rait, 1992). The caregiving role can take a toll on the caregiver. Families may be unable to expend the effort and time necessary to

assist the ill family member with personal and household care and transportation (Carey, Oberst, McCubbin & Hughes, 1991; Oberst, Thomas, Gass & Ward, 1989; Siegel, Raveis, Houts & Mor, 1991). Furthermore, families may not have the financial resources required for home-based care. Caregivers commonly find that they must miss time at work in order to fulfill their caregiving obligations. Others may have to take unpaid leaves of absence and/or sustain job loss. Such requirements take a tremendous toll on the financial resources of caregiving families (Muurinen, 1986; Siegel, et al., 1991). The provision of emotional support may be particularly difficult for family caregivers. In a study by Carey, et al. (1991), emotional support of the patient and others was rated as the most difficult caregiver activity.

Providing care for patients dying of cancer in the home can be a very difficult job for family members. If the shift from hospital-based to home-based caregiving is to succeed, it is imperative that health care professionals consider what the family caregivers need to fulfill their expanded role with as little difficulty and negative impact as possible. But which support system should be meeting which need? Family caregivers may prefer that some of their needs (e.g. scientific and technical knowledge) be met by the formal health care system. They may prefer, however, that other needs (e.g. emotional support) be provided by their informal networks. Little research has been done to obtain the answers to these important questions. Health care professionals must know what family caregivers consider to be their most important needs and their preferences for who should meet those needs. This knowledge will allow the formal

and informal health care systems to work as a team in providing appropriate and cost-effective support for family caregivers.

Purpose

The purpose of this pilot study is to begin to determine: 1) the support needs of family caregivers of advanced cancer patients in the home and, 2) family caregivers' preferences for who might best meet these needs. How well these needs are being met and which support system or systems is/are currently meeting these needs will also be assessed. The results of the research project will add to what is already known about the needs of family caregivers of advanced cancer patients at home and will add some insight into the vital role of the informal support system in this population. This pilot study will also test the feasibility of the research protocol in preparation for a large-scale study of family caregivers' needs and preferences.

Conceptual framework

The Neuman Systems Model was used as the conceptual framework for this study. The Neuman Systems Model (Neuman, 1995) is a conceptual framework that supports a broad view of what constitutes a client; an individual, a family, or even society itself. The client is considered to be an open system in continuous contact and interaction with the environment. In this study, the family unit is considered to be the client. The environment is anything with which the system interacts. The two main aspects of the model are environmental stressors and how the client system reacts to the stressors.

There are three categories of stressors. Intra-personal stressors are forces acting from within the system. For family caregivers of home-based clients with cancer, intra-personal stressors could include feelings of inadequacy and fear. Inter-personal stressors, such as interactions between the client system and their support network, act from outside of the system, but are closely related to the system. An inter-personal stressor would be when health care professionals are not providing family caregivers with enough information to care properly for their ill loved one. The last type of environmental stressors are called extra-personal. They include all stressors which are distant to the client system. A good example of extra- personal stressors is the availability of community resources, such as respite services for the family caregivers.

According to Neuman (1995), the ultimate goal of the client system is to maintain stability in order to protect the basic structure of the system. This is done by adjusting to, interacting with, or changing the environment in the best way possible to maintain system equilibrium. There are two main ways that stability is maintained. The first is called the flexible line of defence. It is a constantly changing buffer zone which is used to stop stressors from influencing the system, thereby preventing a stressor reaction and subsequent system instability. The effectiveness of the flexible line of defence can be influenced by many factors; such as, in human beings, fatigue, or an overwhelming number of stressors impacting the system in a short period of time or for a prolonged time. Examples of flexible line of defence functions in the family caregiver population are previous caregiving experiences and effective coping mechanisms. Types of coping

mechanisms include seeking out necessary information and talking to someone about stressful feelings.

If a stressor successfully penetrates the flexible line of defence the usual wellness state of the system, called the normal line of defence, is impacted. This causes the second mechanism the system has of maintaining stability to respond. These are called the lines of resistance and are the resources that the client system uses to protect the basic structure of the system. A possible example of a line of resistance in family caregivers of cancer clients is the autonomic nervous system, (eg. increased blood pressure) being activated to defend against a physical or emotional threat to the body.

The explanation of the conceptual framework clearly demonstrates the value of the Neuman's System Model to guide this research study. As shown, the needs (stressors) of family caregivers must be identified and how well the needs are being met must be determined. It is also important to determine who the caregivers want to help meet these needs. When this information is known, steps can be taken to help meet the needs appropriately, resulting in an increase of family caregivers' flexible lines of defense. If these needs are not met adequately, eventually the family caregivers' normal lines of defense will be impacted, causing an activation of their lines of resistance. When these lines of resistance are depleted the family caregivers will be unable to fulfill their caregiving roles or, at least, be severely hampered in their caregiving roles because of subsequent physical illness or physical and/or psychological exhaustion.

Definitions

Social Support - the provision of emotional, tangible, or informational assistance among people (Schaefer, Coyne, & Lazuras, 1981).

Formal support system - "All governmental and voluntary service agencies, as well as health and other service professionals and paraprofessionals that work on their behalf (Chappell, Strain & Blandford, 1986, p. 89)". For the purposes of this study, the formal support system will be composed of the following categories: nurse; physician; para-professional, other health care professionals including pharmacists, physical therapists, occupational therapists, etc.; and support aides.

Informal support system - All people who provide assistance without professional status and who are not receiving financial remuneration. For the purposes of this study, the informal support system will be composed of the following categories: spouse, son/daughter, relative, friend, neighbor, and clergy. Clergy have been included in this category because, although they are professionals who get paid to perform a service, they are not often considered to be part of the health care team.

Family - "One or more individuals closely related by blood, marriage or friendship" (Mallinger, 1989, p. 26).

Informal Caregiver - "An unpaid person, identified by the patient with cancer, who helps the patient with physical care or coping with the disease process" (Hileman, Lackey, et al., 1992, p. 772).

Need - "A condition which (is/)was important to the subject and that is(/was) not being satisfied in the subject's present environment (Hileman, Lackey, et al., 1992, p. 772)".

Research questions

The investigation will answer five questions:

1) What are the demographic characteristics of persons who provide home-based care of clients with advanced cancer?

2) What are the support needs of home family caregivers of advanced cancer clients?

3) How well are the support needs of home family caregivers being met?

4) Which family caregiver needs are being met by which support system/s?

5) Which support system/s would the family caregivers prefer to meet their needs?

Limitations

Because this study is a descriptive study with only ten participants, there can be no generalization to the population of home-based caregivers of patients with advanced cancer (Buckwalter & Maas, 1989). The results can only be used to describe the small population which was studied, to evaluate the accrual and research methods, and to suggest possible directions for further research.

Chapter Two

Literature Review

Considerable research has focused on the needs of cancer patients and their family caregivers. This research has focused on the identification and description of needs, the examination of how well needs are being met by caregivers and what patients and family caregivers want from nurses and other health care professionals. Little research, however, has focused on how the informal support system is helping to meet family caregiver needs and what role family caregivers actually want the informal support system to fulfill. A review of the relevant literature in these areas is important to clarify what we know about family caregiver needs and to identify any gaps that remain.

Who are the home-based family caregivers of persons with advanced cancer?

The demographic characteristics of home-based family caregivers of advanced cancer patients have been described by many researchers. These characteristics are relevant because some of the needs of family caregivers may directly relate to those characteristics. Forty percent (Northcott & Northcott, 1997) of Albertans 18 or more years of age provided informal support to family members. Included in that support was home/personal care, emotional care, transportation, household chores, finances and child care. One percent of Albertans stated that they provided palliative care. We know that in most cases more than one person is involved, to varying degrees, in caregiving, but there is usually one person who has the primary responsibility of co-

ordinating and providing direct care (Given & Given, 1996). The primary caregiver is most often female (Given & Given, 1996; Laizner, Yost, Barg, & McCorkle, 1993), usually a wife caring for a husband or a daughter caring for a parent (Given & Given, 1996). According to Given and Given (1996), family caregivers tend to be over 55 years of age. Laisner, et al. (1993), in a review of the needs research on family caregivers of cancer patients from 1982 to 1992 reported a mean caregiver age of 61 years and that women taking care of spouses and parents were the main caregivers.

What are the support needs of home-based family caregivers of patients with advanced cancer?

Previous research in this area has been done in two ways. The needs of caregivers and patients have been studied together and the needs of family caregivers have been studied separately.

Needs of caregivers and patients. Some needs research has focused on comparisons among professionals', patients' and family caregivers' perceptions. These comparisons allow us to get a sense of the accuracy of needs assessments by various partners in the health care team and to determine whether accurate needs assessments can be made by anyone other than the person whose needs are being assessed. Garland, Bass and Otto (1984) compared the importance rankings of patient and caregiver needs by the caregiver and nurses and found high levels of agreement at the beginning of hospice care. This agreement increased over time. Wingate and Lackey (1989) attempted to identify and classify the needs of cancer patients and their home caregivers from the

point of view of patients, caregivers and nurses. Nurse experts used q-sort methodology to place need statements into the categories of information needs, household management needs, physical needs, psychological needs, spiritual needs, legal and/or financial needs, and other needs. The needs of the patients and family caregivers were the same except that family caregivers also identified respite needs.

Blank and colleagues (1988) conducted a descriptive study of the stressors of patients and their family caregivers. The study was based on the Newman Systems model. The stressors were classified as either intra-personal, inter-personal or extra-personal. Intra-personal stressors of family caregivers included treatment uncertainty, role conflicts, coping problems, and emotions such as fear and guilt. Inter-personal stressors were the lack of support and lack of information. Transportation and finances were considered extra-personal stressors.

Another area of study has been the identification of needs of patients and their family caregivers. The identification of specific needs of family caregivers must be known before implementing any action to meet the needs, according to Grobe, et al. (1982) and Blank, et al. (1988). If these needs are not known, then steps cannot be taken to meet them. Although researchers have often examined the needs of patients and their caregivers in the same study, only the needs of the family caregivers will be discussed here.

In their study of advanced cancer patients and their families, Grobe, Ahmann and Ilstrup (1982) showed that family caregivers reported the need for more services than did patients. In particular, families required more in-home medical monitoring, and

more information about available community services. They also needed more emotional support and recreation. The most important need for the caregivers in a study by Longman, Atwood, Sherman, Benedict and Strang (1992) was to be assured that the patient was comfortable. Other caregiver needs focused on involvement with health care, including up-to-date information about the client and access to physicians and hospital treatment if necessary.

Hileman and Lackey (1990) partially replicated Wingate and Lackey's study (1989), described earlier, by obtaining need statements from patients and caregivers, but not from nurses. Nurse experts organized the need statements into the categories previously used by Wingate and Lackey. Caregivers ranked psychological needs as most important (Hileman & Lackey, 1990; Wingate & Lackey, 1989). The categories would have had increased validity if patients and caregivers had also been asked to conduct the Q-sorts.

Needs of family caregivers. A number of studies have focused on the relative importance of family caregiver needs. Research indicates that the need for information is common, particularly relating to caregiving skills and treatments (Hinds, 1985). In their study of family caregivers of advanced cancer patients, Grobe, Ilstrup and Ahmann (1981) found that family members most needed to learn about ambulation, bowel management, comfort care, dietary control, pain management, and wound care. They found that family caregivers often learned these skills through trial and error (1981). Ferrell and Schneider (1988) found that pain is commonly managed ineffectively at home and that caregivers needed more information about pain control.

The primary reason for the poor pain control is because of inaccurate beliefs about narcotic analgesics, including fears of addiction and tolerance, on the part of both patients and families. Seventy percent of patients claimed that their pain was more severe at home than in the hospital (Ferrell & Schneider, 1988). Family caregivers also required more information about available community services (Grobe, et al., 1982; Hinds, 1985).

In a study by Tringali (1986) a list of needs of the family members of non-terminal cancer patients was placed into three categories: cognitive, emotional and physical. The respondents were three groups of family members who were grouped according to the stage of the patient's disease: initial, ongoing, and follow-up treatment. Respondents were asked to rank order the needs according to their importance. For all three groups of respondents, information needs tended to be ranked as most important, followed by emotional needs. The family members considered their own physical needs to be least important. A clearer explanation of what constituted the three need categories would have been helpful.

Informational and psychological needs were of greatest importance to home caregivers in a study by Hileman, Lackey and Hassanein (1992). The questionnaire used was the Home Caregiver Need Survey (HCNS), previously developed by Hileman and Lackey (1990). An important finding in this study was that, according to the 42 respondents that completed all three of the questionnaires, family caregiver needs and needs' satisfaction changed over time. The variables were measured three times within nine months. According to the degree of agreement between the respondents' three

questionnaires, the areas of change, arranged from least to greatest, were spiritual needs, patient care needs, personal needs and household needs. The change was greatest over the first three months. There was less change with informational needs, psychological needs, and those needs involving children.

Two other studies also used the HCNS. Harrington, Lackey & Gates (1996) compared caregiver responses of hospice cancer patients and clinic cancer patients. They determined that the needs in the information and the spiritual sub-scales to be the most important for both caregiver groups. Hospice caregivers were more satisfied about how well their information needs were being met than were clinic caregivers. Steele and Fitch (1996) studied Canadian family caregivers of home hospice cancer patients. The needs with the highest Barrier Need Scores, indicating the most important needs which were the least well satisfied, were 'time for myself away from the house' (household need) and 'time for my personal needs' (personal need). Two other personal needs, 'time to rest' and 'adequate sleep' were also identified. 'Ways to help my patient maintain some independence' (patient care need) and 'a caregiver hotline' (household need) were also important needs.

Hinds (1985) used interviews to determine the needs of family caregivers of cancer patients. Two main areas of need were identified: physical care of the patient (mainly focusing on informational needs about physical care), and psychosocial needs. Included in the psychosocial needs category were financial, affective, psychological and respite needs.

It has been determined that family caregivers of patients with cancer have many needs. In all of the studies, except for Steele and Fitch (1996) which presented Barrier Need Scores only, informational needs were very important. Psychological needs were also important, except in Harrington, Lackey, and Gates (1996). It is possibile that in this study the high spiritual need satisfaction may have influenced the scoring of the psychological need sub-scale. The personal needs sub-scale was ranked higher in the two studies, Steele and Fitch (1996) and Harrington, Lackey, and Gates (1996), that had respondents whose family members were more acutely ill and in hospice care. A finding in Hileman, Lackey and Hassanein (1992) may help to explain this issue. They found in their study that as client activity decreased, family caregiver personal needs increased. In other words, when the family caregiver is required to provide more care for their loved one, there is an increased burden on them and they find that their personal needs become an issue.

How well are family caregiver needs being met?

Given the identification of the needs of family caregivers, researchers began to focus on how well these needs had been met. Some of the researchers focused on whether needs had been met, other researchers focused on levels of satisfaction with care.

In a study conducted two to four months after the death of their loved ones, family members were interviewed about their needs in the last month of caregiving (Jones, Hansford & Fiske, 1993). Although the vast majority of the caregivers classified the

support that they received as ranging from good to excellent, they stated that some needs had been poorly met. More information was required in the area of finances and available community resources. The caregivers believed that home care services, such as cleaning, should have been introduced sooner and more basic information about patient care and medical/nursing procedures would have been useful.

Nalewajek (1992) studied what family members felt were the most supportive nursing actions and their satisfaction with the care in terminal cancer. The study was undertaken on two active care units of a cancer hospital. Generally, family members were very satisfied with the care, in particular with pain control and how comfortable they were made to feel. The things which the families were least satisfied with were family conferences and not being included in decisions about patient care.

Kristjanson conducted a series of studies investigating nursing actions which indicate quality of palliative care to patients' families. The first study (1986) used structured interviews to elicit from family members of patients on a palliative care unit those nursing actions that were deemed most and least important when caring for the patients and family members. Seventy-four nursing behaviors were identified as important when caring for the patient and 77 were identified regarding family care. In the next study (Kristjanson, 1989), 210 family members of palliative care patients used Q-sort methodology to rank the responses obtained in the first study. Patient caring behaviors were ranked separately from the family caring behaviors. The most important nursing care behavior chosen in relation to the patient was relief of pain. The other common responses indicated that it was important that the patient is provided

with the best medical care possible. Responses indicating a need for information were the most important for family care. The third phase of the research was to develop a tool to measure family members' satisfaction with palliative nursing care.

How well family caregiver needs are being met was investigated in this part of the literature review. Generally, family members were satisfied with how well their needs were met by health care workers. Some needs which were less well satisfied included information about basic patient care, pain control and availability of community resources. No studies were identified which investigated how well the informal support system met family caregiver needs.

Effects of unmet needs on Family caregivers

Concerns about the burdens which this new caregiver role may be placing on caregivers has stimulated a large amount of research in this area. For example, we know that these burdens may affect the health of family caregivers (Stetz, 1989). However, caregiver perception of health may be influenced positively by an increased sense of purpose and negatively by caregiver uncertainty (Stetz, 1989). Petrick (1991) discovered that four factors negatively influenced the perceived health of spouses of cancer patients: 1) difficulty managing the caregiver role, 2) being a caregiver for less than a year, 3) being a young caregiver with higher than average socioeconomic status, and 4) the presence of metastases in the cancer patient. Importantly, Petrick's study also discovered some positive aspects to family caregiving. The caregivers were pleased that they could be of help to the family member and welcomed the chance to

reciprocate previously received assistance. They also felt that they had grown through the experience, were more in control of the caregiving situation, and were better able to maintain their usual lifestyles. Unfortunately, many more burdens are identified in the literature than benefits. It is hypothesized (Kramer, 1997) that more burdens are identified than benefits because previous research has focused on the negative aspects of caregiving. Currently, research is being undertaken looking for the advantages of the caregiving role.

One study (Fakhoury, McCarthy & Addington-Hall, 1996) found three characteristics in those caregivers of cancer patients who were most satisfied with the caregiving experience. The first characteristic was that the caregivers considered the caregiving experience to have been rewarding. Second, caregivers were most satisfied when all of their needs were met while caring for the patient. Finally, family caregivers who felt that their health after the death of the patient was excellent felt satisfied with the caregiving experience.

Providing care in the home for patients dying from cancer can be a very difficult job for family members. The caregiving role can have a hazardous effect on all aspects of life, including finances and emotional and physical health. It is assumed that these dangers can be minimised if health professionals and the family's informal support system meet as many needs as possible experienced by family caregivers while performing their caregiving roles. While there are many caregiving needs, three basic categories of needs; emotional support, information, and physical support; will be discussed here.

Emotional support is required by family caregivers. It is extremely painful to care for a loved one who is physically and/or mentally deteriorating, especially knowing that despite one's best efforts and intentions, there is little that can be done to improve the patient's health (Gates, 1993). Family caregivers report feelings of inadequacy and helplessness (Ferrell, Johnston Taylor, et al., 1993).

Depression can be a problem. Greenly (1982) found that there were higher depression levels present in family members of people who were dying of cancer at home than if they were dying in the hospital. It is also suggested that family caregivers are more likely to experience depression if the cancer patient is in pain (Miakowski, Kragness, Dibble & Wallhagen, 1997), or depressed (Kurtz, Kurtz, Given & Given, 1995; Given, Stommel, Given, Osuch, Kurtz & Kurtz, 1993). However, how well family members cope with the caregiving role and the amount of support they perceive can reduce depression levels (Schumacher, Dodd & Paul, 1993). Given, et al (1993) and Kurtz, et al (1995) discovered that caregiver optimism was associated with lower levels of caregiver depression.

Information and instruction are necessary to prepare the family for their caregiving role (Cawley & Gerts, 1988). In particular, family caregivers need information on how to provide personal care (Cawley & Gerdts, 1988; Grobe, Ilstrup & Ahmann, 1981), pain management (Dar, Beach, Barden & Cleeland, 1992; Ferrell, Johnston Taylor, et al., 1993; Yeager, Miakowski, Dibble, & Wallhagen, 1995), and parenteral infusions (Bruera, 1990; Peplin, 1989). This information is especially important in light of all the new technology which is now used for cancer patient care.

Family caregivers also require the opportunity for respite (Hinds, 1985; Bramwell, MacKenzie, Laschinger & Cameron, 1995; Strang, 1995). As mentioned earlier, a great deal of time may be required for all of the many aspects of caregiving (Siegel, et al., 1991). Caregiver exhaustion is a major reason why hospice patients are admitted into hospitals (Bramwell, MacKenzie, Laschinger & Cameron, 1995). Time for personal care, such as rest and nutrition, is necessary to ward off undue stress and fatigue which can have a negative affect on the caregiver's health status (Hull, 1990; Wykle, 1994).

Moderate to severe fatigue has been reported by family caregivers (Jensen & Given, 1991). Jensen and Given (1993) discovered that fatigue is not related to caregiver age, the amount of employment outside of the home, or the length of time in the caregiving role. How many hours of care was required and how much that care impacted the caregiver's daily schedule did affect caregiver fatigue. Caregiver burden increases if adequate help is not provided to enable caregivers to give the assistance required by the patient (Buehler & Lee, 1992). Respite is crucial to help relieve caregiver burden (Hinds, 1985; Bramwell, MacKenzie, Laschinger & Cameron, 1995; Strang, 1995).

Who is currently meeting family caregivers' needs?

The roles of health care professionals and informal networks in meeting caregivers' needs is an important consideration for understanding how caregivers' needs might be met. As will be seen in this section, much of the focus of research has been on the roles of health care professionals, especially nurses. Hull (1990) reported a study

where qualitative interviews were done with family caregivers of patients in a hospice home-care program before and after the patient's death. The four areas in which the family caregivers considered nurses to be caring were: being available to be contacted 24 hours a day, being clinically competent, having a non-judgemental attitude, and communicating effectively. According to Nalewajek (1992), three nursing actions which the family felt were the most supportive were: providing time for the patient and family members to be alone, efforts to make the patient comfortable, and allowing family members to help with the physical care of the patient. The three least supportive actions were considered to be: giving hope, talking to the patient about his or her fears, and allowing family members to talk about their feelings. In Hull's (1990) study the family members also appreciated the nurses for providing emotional support for them, but only when they wanted to share their feelings. The family did not find it helpful when the nurses encouraged them to share their feelings if they were unwilling. Family members felt that "being reassured [that] the patient was adequately cared for took priority over having their own needs met" (p.54). This statement indicates that the family caregivers rank their needs, however great they may be, as having less importance than those of the client.

Q-sort methodology was used in four studies to identify helpful nursing behaviors. Three of the studies used the same nurse behavior statements which had been predetermined from the literature. In the first study (Skorupka & Bohnet, 1982), family caregivers were asked to rank 75 nursing behaviors using the q-sort method. The behaviors were classified into three groups: those related to the physical needs of

the patients, the psychosocial needs of the patient, and the psychosocial needs of the caregiver. McGinnis (1986) used the same list of nursing behaviors, but after consultation with Skorupka reduced the number of behavior statements to 60 to make the task of sorting easier for the family caregivers. Ryan (1992) asked family caregivers and hospice nurses to Q-sort the same 60 nursing behaviors used by McGuinnis. In Ryan's study the caregivers ranked the clients' psychosocial needs as most important and the clients' physical needs as second. Skorupka and Bohnet did not report whether the clients' physchosocial or their physical needs were considered more important. In both studies the least helpful nursing behaviors were related to the psychosocial needs of the caregivers. However, the caregivers in McGuinnis' study felt that the least helpful nursing behaviors were in the area of the patient's physical needs. The most important needs in this study were clients' psychosocial needs, followed by the caregivers' psychosocial needs. All of the family caregivers considered that the most helpful nursing behaviors were those which focused on the psychosocial needs of the patient. A finding in Ryan (1992) may help to explain why the physical needs of the client were ranked relatively low. Nurses were considered more helpful in meeting the physical needs of the client than with any other needs. The caregivers may have ranked the physical needs of the client as lower because the nurses were meeting those needs very well.

The fourth study which used Q-sort methodology was undertaken by Freihofer and Felton (1976). They asked 25 patients dying of cancer and their family caregivers to Q-sort 88 predetermined nursing behaviors. These behaviors were also divided into

three categories, similar to the three categories used in the other studies: actions related to the comfort and hygiene of the patient, the emotional needs of the patient, and the emotional needs of the family member. The least desirable nursing behaviors were psychosocial measures directed at the family; such as: "encourage me to cry," "hold my hand," "cry with me," and "remind me that the patient's suffering will be over soon." Again, the responses indicated that nursing behaviors which focus on the patient rather than the family is preferred.

Lewandowski and Jones (1988) studied helpful nursing interventions toward hypothetical cancer patients and families during the initial, adaptation and terminal phases of living with cancer. Three similar vignettes were used, one representing each phase. A stratified, random sample of 62 respondents was obtained from a telephone directory. They were asked to imagine themselves to be the family members of the person in the vignette and to rate 28 nursing behaviors, using a five-point likert scale which was labelled least helpful and most helpful. Consistently throughout the phases, the respondents scored interventions which focused on the patient more highly than those which centered on the family member. Also, nursing behaviors which provided information to either the patient or the family members were rated highly in all phases. The least helpful nursing behaviors, which focused on emotional and psychosocial needs of the family caregivers, were the same as were identified in the study by Freihofer and Felton (1976). A likert-type scale was also used for another study about nursing behaviors which helped the family members of cancer patients cope (Welch,

1981). Again, the family members reported a preference that nursing care be directed toward patients, not themselves, and that nurses provide more information.

What are family caregiver's preferences for who should meet their needs?

This final section of the literature review looks at what the family caregivers of cancer patients felt should be the support role of nurses in meeting their needs. Invariably, family caregivers felt that nurses should focus their attention on the needs of the patients and provide the best care possible. Also, the provision of information was considered to be an important aspect of the nurses' support role. According to family caregivers, the expected role of nurses usually did not include the provision of emotional or psychosocial support to family caregivers. However, if family members do not want nurses to meet emotional and psychosocial needs, then who, if anyone, will they allow to assist them in these areas? This is an especially relevant question considering that emotional and psychosocial needs have been identified as being important to family caregivers.

Although it is recognized that the informal support system, such as relatives, friends, and neighbors, should and does play a large part in meeting the needs of caregivers (Hinds, 1985), relatively little is known about what is actually involved in this support role. Considering the current trend of moving as many health care services as possible into the community, this information is crucial. The shift from hospital-based to community-based care has placed greater responsibility for patient care on the family. Family members are often inadequately prepared to undertake the caregiving

role. As such, if the family members do not have their needs met adequately, they will have difficulty providing the care necessary for their loved ones.

Chapter Three

Method

Sample

The sample in this pilot study included ten participants. They were recruited through the Capital Health Authority Home Care Program, a hospice day care program, and several church congregations. Originally, a sample size of 53 subjects was planned for this study. The number was based on a calculation using an alpha of 0.05, a moderate effect size of 0.30 and a power level of 0.60 on Kraemer and Thiemann's (1987) two-tail test master table. A sample size this large would have allowed some correlational statistical analysis to be done. Unfortunately, subject accrual was very slow, primarily because some of the health care staff were hesitant to speak to the clients about the study. They felt that the study could have increased the stress that these families were already under. Therefore, with the permission of my thesis supervisor, data collection stopped after one year.

Criteria

Caregivers who participated in the study were identified by their palliative family members. Caregivers were included if they were able to speak, read, and understand English and were willing to participate in the study. The caregiver had to have provided care for at least one month.

Instruments

Caregiver needs. An adaptation of Hileman's Home Caregiver Need Survey (HCNS) (Hileman, Lackey, et al., 1992) was used to gather the data (Appendix A). The HCNS was based upon qualitative research of home-based family caregivers of advanced cancer patients and focused on family caregivers' identification of their needs (Hileman & Lackey, 1990).

This self-report questionnaire is composed of 89 need statements divided into six subscales. The NEEDS INVOLVING INFORMATION SUB-SCALE includes 14 statements, such as 'information about what symptoms to expect' and 'information about drugs', mainly relating to information about the client, the disease process, medications and treatments. The NEEDS INVOLVING YOUR HOUSEHOLD has 12 statements involving help needed to manage the household and day-to-day domestic concerns. Examples of these needs include 'help with housework' and 'help with transportation'. There are 16 statements in the CLIENT CARE NEEDS SUB-SCALE. These statements relate to what is needed to provide physical and emotional care for the client, including 'methods of pain control' and 'ways to reassure the family member'. The 11 statements in the PERSONAL NEEDS SUB-SCALE focus on the needs of the family caregivers. Examples of this sub-scale are 'time to rest' and 'support from my family'. The SPIRITUAL NEEDS SUB-SCALE'S six statements address the religious, existential and spiritual needs of the family caregivers, including needs such as 'hope for the future' and 'prayer from others'. The PSYCHOLOGICAL NEEDS SUB-SCALE involves 30 needs which focus on emotions of family caregivers, some

kinds of information, finances and interactions with others. 'Ways to decrease stress' and 'information about funeral planning' are examples of these needs.

Adaptations to the HCNS were made to allow respondents to identify who currently meets each of the needs, and to identify who would be preferred to meet the needs. The tool was adapted for this study by adding two columns labelled 'who is meeting the need for you?' and 'who would you prefer to meet the need?' Two likert-type scales allowed family caregivers to rate the importance of each need and to evaluate how well the need was being satisfied (Hileman, Lackey, & Hassanein, 1992). The need statements were changed slightly. The word 'patient' was changed to 'family member' to better reflect the community setting. In addition, some words in the section on spiritual needs were changed: 'church' was changed to 'place of worship', 'clergy' was changed to 'spiritual leader' and 'God' was changed to 'Supreme Being'. These changes make the questionnaire more inclusive for people who come from a wide range of faith backgrounds. Although in the questionnaire the term 'family member' was used to indicate the person with cancer, for the purpose of clarity they will be referred to as 'client' when the findings of this study are reported and discussed. The tool is comprehensive and capable of obtaining data about formal and informal support roles

The need statements in the HCNS had been determined from 531 need statements obtained from 15 patients and 15 family caregivers in three previous descriptive studies of cancer patients and their caregivers. After eliminating duplication, three nurse experts and three English language experts demonstrated 90.10% agreement on the remaining 98 items (Hileman, unpublished manuscript). These items were arranged

into six predetermined need categories (Wingate & Lackey, 1998). Construct validity was established through principle factor analysis with promax rotation and resulted in only minor changes in the sub-scale placement of needs (Hileman, unpublished manuscript). Cronbach alpha coefficients reported range from 0.87 to 0.96 on the six subscales. A Cronbach theta coefficient, a special kind of Cronbach alpha coefficient (Carmines & Zeller, 1979) was 0.98 (Hileman, Lackey, & Hassanein, 1992). The final stage in the development of the questionnaire was to make five small changes which allowed the questionnaire to be utilized with the family caregivers of any patient population (Hileman, unpublished manuscript).

The HCNS provides three scores (Hileman, et al., 1992): one representing the importance of the need (I), one representing the satisfaction of the need (S), and one barrier need score (BNS). The BNS was calculated by multiplying the I with a reverse score of the S. The BNS can range from 7-49, with a high BNS representing an important need which is not being satisfactorily met.

Depression. The second edition of the Beck Depression Inventory (BDI-II) (Beck, Steer, et al., 1996) (Appendix B) was used to determine the depression level of the caregivers. The BDI-II is a 21 item self report questionnaire which is used to measure depression in people 13 years of age or older. It is an effective measure of depression for both depressed and normal populations (Beck, Steer, et al., 1996).

Reliability and validity (Beck, Steer, et al., 1996) have been well established in the BDI-II. Cronbach alpha measures range from 0.73 to 0.95 for this tool, demonstrating internal consistency. Because the questionnaire was developed specifically to measure

the DSM IV diagnostic criteria for depression, it has strong content validity. Construct validity has been established through comparison with other depression scales, such as the Beck Hopelessness Scale (r=0.68) and the Revised Hamilton Psychiatric Rating Scale for Depression (r=0.71).

The BDI-II (Beck, Steer, et al., 1996) is easily scored. Each item of the BDI-II is scored on a four point scale from zero to three. The separate item scores are added together to determine an overall total score. The highest possible score is 63. There are four categories of depression determined according to the total scores the subjects obtained on the questionnaire. Respectively, the four category cut-off scores used to determine clinical depression are: (a) minimal - 0-13, (b) mild - 14-19, (c) moderate - 20-28, and (d) severe - 29-63. These cut off scores were established to minimize false-positive and false-negative scores.

Demographic Data. Demographic data on patients and caregivers were collected (Appendix C). Family caregiver data included caregiver's marital status, age, gender, education, occupation, changes in employment status since becoming a caregiver, income, relationship to the patient, ethnic background, religion and amount of time spent providing care. Information solicited about the patient included: diagnosis, time of diagnosis, age, and gender.

Procedure

Ethical clearance to undertake the study was requested from the University of Alberta Ethical Review Board, from Home Care and from the hospice day program

(Appendix D). Recruitment proceeded when ethical clearance and administrative approvals were granted. In the case of Home Care, clients were contacted by health care staff to ensure their willingness to be contacted by the researcher. Prior to contact with the clients, their physicians were contacted via fax and requested to respond in writing or fax by a certain date if they had any concerns about their clients being involved in the study. Once the physicans provided approval, the clients were contacted. Members of church congregations were accrued through clergy or through church programs such as Pastoral care. If the clients expressed willingness to be contacted by the researcher, either an information letter (Appendix E) was sent to the clients or a phone call was made (depending on client choice) explaining the study and asking the clients if they would like to participate. After two weeks, if a letter was sent, those clients who did not refuse to participate were contacted by telephone. If they were interested in participating, they were asked to identify their primary family caregiver. Caregivers were contacted through an information letter (Appendix E) and asked to contact the researcher by telephone if they did not want to participate in the study or if they wanted more information. If they did not refuse to participate within two weeks, the researcher contacted them by telephone to offer further information and to invite them to participate. If they consented, arrangements were made to get the consent form signed (Appendix F) and complete the questionnaires. In the majority of cases, however, the home care staff, clergy and day program manager obtained the approval of both the client and the primary caregiver prior to informing the researcher about the potential study subject. Questionnaire completion was done at a time and

place mutually agreed upon: in the client's home in all but two cases. The questionnaires were completed in the researcher's presence, which allowed for clarification of the questions and procedure for the caregiver.

Ethical considerations

The investigator personally explained the study to the participants and answered any questions that they had. They were assured that participation was voluntary, that they could withdraw at any time, and that they did not have to answer any questions that they did not want to answer. Family caregiver consent forms were stored in a separate locked drawer away from the questionnaire data. Client consent was assumed by provision of information about their family caregivers. Only the researcher knows the names of the participants, and the questionnaires are identified by number only. All data are reported in aggregates only as a further attempt to maintain the anonymity of the participants.

Data Analysis

Descriptive statistics were used to analyze the data obtained from the HCNS, the BDI-II, and the demographic information sheet. Appropriate measures of central tendency, dispersion, and cross-tabulations were performed on the variables. No correlational analysis was possible because of the small sample size. The data were organized and presented in ways that displayed any patterns which were present.

Cronbach alphas on the total HCNS and the separate subscales were calculated to determine the internal consistency of the measures for this sample.

In order to best discover any underlying patterns in the 'who is meeting the need' and 'who is preferred to meet the need' columns, the need statements in each sub-scale were divided into sub-categories. Similar needs in each sub-scale were grouped together. The NEEDS INVOLVING INFORMATION SUB-SCALE was divided into four sub-categories: 1) Information Regarding Medications and Treatments, 2) Information Regarding the Client and Disease, 3) Information Involving Others, and 4) General Information. Two sub-categories were created from the NEEDS INVOLVING YOUR HOUSEHOLD SUB-SCALE. These were: Practical Household Needs and Personal Household Needs. The CLIENT CARE NEEDS SUB-SCALE was divided into the sub-categories of Food and Nutrition, Comfort, Direct Help, Psychosocial, and Extra Needs. Independent Needs and Needs Involving Others were the two sub-categories made out of the PERSONAL NEEDS SUB-SCALE. The SPIRITUAL NEEDS SUB-SCALE also had two aspects: those that could be met personally and those that needed to be met by others. The final sub-scale (PSYCHOLOGICAL NEEDS) was divided into four sub-categories: Emotional, Information, Psychological Needs Involving Others, and Financial. Please see Appendix G for a list of the need statements and the sub-categories into which they were placed.

CHAPTER FOUR

Findings

In this chapter, the results of the descriptive pilot study are presented. The data sources are the demographic questionnaire, the BDI-II, and the adapted HCNS.

Demographics

There were ten family caregivers (two men and eight women) who took part in the study. Two of them were recruited through church congregations, three through the hospice day program, and five from palliative home care programs. Their ages ranged between 30 and 80 years with the mean age of 57.5 years. Six of the caregivers, two husbands and four wives, were the spouses of clients with cancer. Two of the other three married caregivers were daughters of clients who were either widowed or divorced. One caregiver was the niece of a client, neither of whom was married. All of the caregivers, except for one daughter and the niece, lived with the client. Except for the niece, who provided five hours of care a week, all caregivers provided at least 30 hours of care per week for their ill family member. Eight of the caregivers classified themselves as Protestants and two said that they were of the Roman Catholic faith. Seven of the caregivers had at least a high school level of education. Three of the family caregivers, two daughters and the niece, worked full-time. One daughter worked part-time. One wife had never worked outside of the home. The remaining five caregivers, two men and three women, were retired. The age range of those who were still working, either full or part-time, was 30 to 47 years. Those caregivers who

were retired had an age range between 63 and 80 years. There was no change in the work status of any of the caregivers in response to the caregiving role. Of the eight caregivers who responded to the question about income, six of them had an annual income of $21,000 or more, ranging from $21,000 to greater than $50,000/year. The other two caregivers had an annual income of $20,000/year or less.

The ten clients, six men and four women, had all received their original diagnosis of cancer since 1990. The primary sites of the cancer were the breast, liver, bladder, melanoma, prostate, lung and pancreas; all of which, except the liver, are common major cancer sites in Alberta (Canadian Cancer Statistics, 1998). Eight of the clients had metastases in at least one of the following common sites: brain, liver, bone, lung, esophagus, breast, or prostate. The ages of the clients ranged between 57 and 84 years with a mean age of 73.3 years.

Beck Demographic Inventory

According to the BDI-II Manual (Beck, Steer, et al.,1996) there are four categories of depression determined according to the total scores the subjects obtained on the questionnaire. Respectively, the four category cut-off scores used to determine clinical depression are: (a) minimal - 0-13, (b) mild - 14-19, (c) moderate - 20-28, and (d) severe - 29-63. According to the BDI-II, eight of the caregivers were minimally depressed, with scores ranging between one and thirteen, and two were mildly depressed, with scores of fifteen and seventeen. None of the caregivers was moderately or severely depressed, according to the BDI-II.

Health care needs

The data from the modified HCNS was examined in three different ways: 1) the ranking of the six need sub-scales in terms of importance, the degree to which they were satisfied and in terms of barrier need scores, these rankings are shown in table 4.1; 2) the needs within the sub-scales were sub-divided into related themes; and 3) the individual needs were examined.

Table 4.1 Rank Order of Need Categories*

Importance	Satisfaction	Barrier Needs
Personal Needs	Personal Needs	Needs Involving Information
Needs Involving Information	Spiritual Needs	Personal Needs
Client Care Needs	Needs Involving Information	Client Care Needs
Spiritual Needs	Client Care Needs	Needs Involving Household
Needs Involving Household	Needs Involving Household	Psychological Needs
Psychological Needs	Psychological Needs	Spiritual Needs

*scores ranked from greatest (importance, satisfaction, barrier) to least

Need importance - sub-scales. The family caregivers' responses on the HCNS determined that they considered their PERSONAL NEEDS to be the most important, with a mean importance score of 6.06 out of a possible total score of seven. The other sub-scales of the questionnaire were ranked according to importance as: (b) NEEDS INVOLVING INFORMATION (mean=5.90), (c) CLIENT CARE NEEDS (mean=5.44), (d) SPIRITUAL NEEDS (mean=5.33), (e) NEEDS INVOLVING

YOUR HOUSEHOLD (mean=4.13), and (f) PSYCHOLOGICAL NEEDS (mean=3.39). Please see table 4.1.

Need importance - sub-categories. The three most important need sub-categories were: (a) Information About the Client and Disease (mean=6.53), (b) Direct Help with Client Care (mean=6.38), and (c) Personal Spiritual Needs (mean=6.28). The three least important need sub-categories were: (a) Practical Household Needs (mean=3.15), (b) Emotional Psychological Needs (mean=3.80), and (c) Financial Psychological Needs (mean=2.10). Please see Table 4.2 for a list of sub-scales and their sub-categories.

Need importance - individual needs. The three separate needs which all ten of the caregivers felt were extremely important (scored seven out of seven) were 'information about how to give medications', 'information about the type and extent of the disease', and 'equipment for patient care'. The three least important needs were 'ways to improve client's appearance', 'spiritual leaders to talk to', and 'help dealing with fear'. The two responses that all ten caregivers felt did not apply to any of them were 'help continuing my children's activities' and 'help with baby sitting', reflecting their life stage.

Need satisfaction - sub-scales. The family caregivers were the most satisfied within the sub-scale of their PERSONAL NEEDS (mean=5.59) and least satisfied within the sub-scale of their PSYCHOLOGICAL NEEDS (mean=3.07). They rated the other sub-scales as: (b) SPIRITUAL NEEDS (mean=5.43),

Table 4.2 Sub-scale and Sub-category Mean Scores

Sub-scales and Sub-categories	Importance Scores (mean)	Satisfaction Scores (mean)	Barrier Need Scores (mean)
1) Needs involving information	**5.90**	**4.99**	**13.70**
a) Medications and treatments	6.24	5.42	14.00
b) Client and disease	6.53	5.08	13.33
c) Information involving others	4.27	4.00	7.00
d) General information	6.25	5.25	15.75
2) Needs Involving Your Household	**4.13**	**3.78**	**10.08**
a) Practical household needs	3.15	2.78	8.26
b) Personal household needs	4.03	3.90	8.68
3) Client Care Needs	**5.44**	**4.88**	**10.83**
a) Food and nutrition	4.57	3.83	10.30
b) Comfort	5.37	4.80	10.40
c) Direct help	6.38	5.75	12.45
d) Psychosocial	5.53	4.90	10.80
e) Extra	4.80	4.75	9.10
4) Personal Needs	**6.06**	**5.59**	**12.54**
a) Independent	6.03	4.90	15.73
b) Involving others	6.09	5.99	10.71
5) Spiritual Needs	**5.33**	**5.43**	**7.68**
a) Personal	6.28	6.20	8.89
b) Involving others	4.37	4.67	6.48
6) Psychological Needs	**3.39**	**3.07**	**8.49**
a) Emotional	3.80	3.42	7.05
b) Information	4.09	3.45	9.72
c) Involving others	3.90	2.49	8.66
d) Financial	2.10	1.20	8.40

(c) NEEDS INVOLVING INFORMATION (mean=4.99), (d) CLIENT CARE NEEDS (mean=4.88), and (e) NEEDS INVOLVING YOUR HOUSEHOLD (mean=3.78).

Need satisfaction - sub-categories. The need sub-categories where the family caregivers were the most satisfied were: (a) Personal Spiritual Needs (mean=6.20), (b) Personal Needs Involving Others (mean=5.99), and (c) Direct Help with Client Care (mean=5.75). The three sub-categories where the caregivers were the least satisfied were those that involved Practical Household Needs (mean=2.78), Psychological Needs Involving Others (mean=2.49), and Financial Psychological Needs (mean=1.20). See table 4.2.

Need satisfaction - individual needs. There were no individual needs which all ten of the caregivers rated as extremely satisfied. The three most satisfied needs were 'someone to talk to', 'feedback about proper care of the client', and 'equipment for client care'. The three least satisfied needs were 'time for self away from the house', 'ways to deal with depression', and 'help with housework'.

The Barrier Need Score - sub-scales. The BNS, a measure which indicates both the importance and the satisfaction of a need, showed that the sub-scales which had the least satisfied and most important needs were those involving information. PERSONAL NEEDS were second. Then came CLIENT CARE NEEDS, NEEDS INVOLVING YOUR HOUSEHOLD, and PSYCHOLOGICAL NEEDS. The sub-scale of SPIRITUAL NEEDS had the lowest BNS. Please see table 4.1.

The Barrier Need Score - sub-categories. The needs sub-categories with the highest Barrier Need Scores involved General Information (mean=15.75), Independent Personal Needs (mean=15.73), and Information About Medications and Treatments (mean=14.00). The three needs sub-categories which had the lowest Barrier Need Scores were: (a) Emotional Psychological Needs (mean=7.05), (b) Information Involving Others (mean=10.71), and (c) Spiritual Needs Involving Others (mean=6.48). See table 4.2.

The Barrier Need Score - individual needs. The three separate needs rated as having the highest Barrier Need Scores were: 'information about what symptoms to expect', 'time for personal needs', and 'information regarding treatment side-effects'. The lowest Barrier Need Scores were for the needs of 'a caregiver hotline', 'ways to cope with role changes', and 'help with transportation'.

The Cronbach alpha score for the HCNS in this study was 0.94. The score for the NEEDS INVOLVING YOUR HOUSEHOLD SUB-SCALE was 0.57. The alpha for this sub-scale increased to 0.74 when the need statements 'help with yard work' and 'help with errands' were removed. All of the other sub-scale alpha scores ranged between 0.81 and 0.91.

Support roles

Modifications to the HCNS allowed information about caregiving to be elicited. For each of the needs listed, family caregivers were asked to identify who was actually helping them meet their needs and who they would prefer to be helping meet their

needs. Family caregivers could provide up to three responses for each question. This resulted in a large, unwieldy data set. To increase the meaningfulness of the data set, responses were collapsed into three categories: self, formal caregivers and informal caregivers. Still, the large number of data points made the data difficult to interpret. It was decided that the first response to each need statement might be regarded as the most accurate representation of their situation. For example, if the family caregivers' first of three possible responses to a need statement involved formal personnel, this response was taken to indicate that the formal support system was helping to meet their need and that the formal system was their preference to meet that need. In order to validate this assumption, frequency counts of who is meeting the need and who is preferred to meet the need within each need sub-category were calculated. These calculations showed that the assumption was valid in all but five sub-categories: 'Psychosocial Client Care Needs', 'Extra Client Care Needs', 'Emotional Psychological Needs, 'Psychological Needs Involving Others', and 'Financial Psychological Needs'. In each of these five sub-categories, however, the discrepancies were caused by minor differences only, between the first response to the needs statements and the actual frequency counts for each sub-category.

Sub-category responses for NEEDS INVOLVING INFORMATION

In all of the NEEDS INVOLVING INFORMATION sub-categories, except for the Information Involving Others sub-category, the formal support system is meeting the needs and is preferred to meet the needs. In the case of the Information Involving

Others sub-category, the family caregivers and the informal support system are meeting the needs but the family caregivers would prefer for themselves to meet less of the needs and for the formal support system to meet more of the needs. See table 4.3.

Table 4.3 Responses for sub-categories of INFORMATION NEEDS SUB-SCALE

Need Sub-category	Formal*	Informal*	Self*
Medications and treatments	44.1% (47.9%)	6.0% (2.7%)	5.3% (3.3%)
Client and disease	38.3% (47.5%)	4.1% (0.8%)	4.2% (1.7%)
Information involving others	3.3% (4.4%)	15.5% (15.5%)	18.9% (17.8%)
General information	31.7% (34.9%)	5.0% (0.0%)	3.3% (3.3%)

* scores indicate the percent of responses indicating who currently is meeting the need with preferences in parentheses

Sub-category responses for NEEDS INVOLVING YOUR HOUSEHOLD SUB-SCALE

The Personal Household Needs sub-category was primarily being met by the formal support system. The family caregivers wanted the formal support system to increase their support in this area and the informal support system to also help more. In the sub-category of Practical Household Needs, the informal, and to a lesser degree the formal support systems were helping to meet these needs. The family caregivers want the informal support system to continue to help, but want the formal support system to take on a greater role in meeting these needs. See table 4.4.

Table 4.4 Responses for sub-categories of NEEDS INVOLVING YOUR HOUSEHOLD SUB-SCALE

Need Sub-scale	Formal*	Informal*	Self*
Practical household needs	9.2% (11.2%)	11.8% (10.8%)	3.8% (2.1%)
Personal household needs	18.5% (20.2%)	6.3% (8.1%)	2.6% (1.8%)

* scores indicate the percent of responses indicating who currently is meeting the need with preferences in parentheses

Sub-category responses for CLIENT CARE NEEDS SUB-SCALE

In the sub-categories of Client Care Needs Regarding Food and Nutrition, Client Care Needs Regarding Comfort, and Client Care Needs Requiring Direct Help, the formal support system is meeting the needs and they are preferred to meet the needs. The family caregivers were primarily meeting the needs within the sub-category of Psychological Client Care Needs. The family caregivers would prefer that the formal support system first, then themselves, and finally the informal support system help to meet these client needs. All three of the support systems; informal, formal, and self, equally; were meeting the needs in the sub-category of Extra Client Care Needs. However, the family caregivers would have preferred that the formal support system take a larger role. See table 4.5.

Table 4.5 Responses for sub-categories of CLIENT CARE NEEDS SUB-SCALE

Need Sub-category	Formal*	Informal*	Self*
Food and nutrition	24.5% (26.7%)	2.2% (0.0%)	7.8% (7.8%)
Comfort	20.0% (22.2%)	8.8% (7.7%)	11.1% (11.1%)
Direct help	39.2% (39.9%)	6.7% (8.4%)	5.0% (3.3%)
Psychosocial	12.6% (15.8%)	15.0% (14.2%)	16.7% (15.0%)
Extra	13.4% (15.1%)	13.3% (13.3%)	13.3% (13.3%)

* scores indicate the percent of responses indicating who currently is meeting the need with preferences in parentheses

Sub-category responses for PERSONAL NEEDS SUB-SCALE

The PERSONAL NEEDS SUB-SCALE has two sub-categories. In the Independent Personal Needs sub-category, the family caregivers were both meeting the needs and were preferred to meet the needs. The informal support system was also meeting the needs and was preferred to meet the needs in the sub-category of Personal Needs Involving Others. See table 4.6.

Table 4.6 Responses for sub-categories of PERSONAL NEEDS SUB-SCALE

Need Sub-category	Formal*	Informal*	Self*
Independent personal needs	4.9% (7.5%)	10.8% (12.4%)	23.3% (20.8%)
Personal needs involving others	16.2% (17.7%)	24.9% (28.6%)	10.5% (8.1%)

* scores indicate the percent of responses indicating who currently is meeting the need with preferences in parentheses

Sub-category responses for SPIRITUAL NEEDS SUB-SCALE

There was also agreement between who is meeting the needs and who is preferred to meet the needs in the SPIRITUAL NEEDS sub-categories. Personal Spiritual Needs were being met and were preferred to be met by the family caregivers while the informal support system was meeting and preferred to meet the needs in the Spiritual Needs Involving Others sub-category. These are also the only sub-categories where there is perfect agreement about how much each support system should be doing to meet the needs. See table 4.7.

Table 4.7 Responses for sub-categories of SPIRITUAL NEEDS SUB-SCALE

Need Sub-category	Formal*	Informal*	Self*
Personal spiritual needs	1.3% (1.3%)	11.6% (11.6%)	26.9% (26.9%)
Spiritual needs involving others	1.2% (1.2%)	35.8% (35.8%)	3.7% (3.7%)

* scores indicate the percent of responses indicating who currently is meeting the need with preferences in parentheses

Sub-category responses for PSYCHOLOGICAL NEEDS SUB-SCALE

In the Psychological Needs Regarding Information sub-category the formal support system is meeting the needs and is preferred to meet the needs. Emotional Psychological Needs were being met primarily by the caregivers themselves with some help from the informal support system. The family caregivers would prefer that the informal support system participate equally with them in meeting these needs. The

sub-category of Psychological Needs Involving Others was also being met by the caregivers and the informal support system, and the informal support system was preferred to provide more assistance. In the sub-category of Financial Psychological Needs, both the formal support system and the caregivers were meeting and were preferred to meet the needs. See table 4.8.

Table 4.8 Responses for sub-categories of PSYCHOLOGICAL NEEDS SUB-SCALE

Need Sub-category	Formal*	Informal*	Self*
Emotional	6.0% (6.4%)	11.7% (13.3%)	14.0% (13.3%)
Needs re: information	14.7% (18.7%)	10.2% (9.9%)	8.2% (7.6%)
Needs involving others	6.8% (7.7%)	10.2% (12.0%)	11.4% (11.0%)
Financial	8.3% (8.4%)	0.0% (1.7%)	6.7% (6.7%)

* scores indicate the percent of responses indicating who currently is meeting the need with preferences in parentheses

Summary of sub-category support responses

In the majority of sub-categories, there was agreement between who was actually helping the family caregivers and who would be their preferred helpers. The family caregivers were meeting the needs within the sub-categories of Independent Personal Needs and Personal Spiritual Needs and wanted to continue to meet these needs. The informal support system was meeting the needs within the sub-categories of Personal Needs Involving Others, and Spiritual Needs Involving Others. The family caregivers preferred the informal support system in this role. The other need sub-categories, including: Information About Medications and Treatments, Information About the

Client and Disease, General Information, Personal Household Needs, Client Care Needs Regarding Food and Nutrition, Client Care Needs Regarding Comfort, Direct Help with Client Care, and Psychological Needs Involving Information were being met by the formal support system, and the family caregivers wanted them to continue meeting these needs. In five need sub-categories, Psychological Client Care Needs, Extra Client Care Needs, Practical Household Needs, and Psychological Needs Involving Others, there was disagreement between who is actually meeting the needs and the family caregivers' preferences for meeting the needs.

Examination of the data in this way makes it clear how versatile and resourceful the family caregivers are in getting their needs met. They meet needs themselves, and access different aspects of their formal and informal support system according to what is required.

Support categories

The applicable support responses were also considered without being collapsed into self, formal, and informal. Examples of these support categories are 'self', 'nurse', 'client', and 'family'.

Self. 'Self' is mentioned as helping to meet and is preferred to meet needs in all but the sub-category of Personal household needs. In fact, 'self' is the most frequent 'is meeting' and 'preferred meeting' response in 12 of the 19 sub-categories. Also, whenever 'self' is identified as helping to meet a need in a sub-category, 'self' is

preferred to help meet the need with the same frequency, or more often, with less frequency than they are actually meeting the need.

Client. There are six sub-categories where the client is helping meet the family caregivers' needs. They are Information Involving Others , General Information, Client Care Needs Regarding Comfort, Extra Client Care Needs, Personal Needs Involving Others and Psychological Needs Involving Others. These sub-categories include need statements that require involvement by the client, such as client comfort, a trusting relationship with the client, and client understanding and appreciation of the caregiver. In the first three sub-categories, the caregivers want the client to do less. They want the client to continue to help meet the Extra Client Care Needs at the same level. But in the last two sub-categories, Psychological Needs Involving Others and especially Personal Needs Involving Others, the family caregivers want more client involvement. The Psychological Needs Involving Others sub-category includes need statements such as 'ways to discuss death with family member' and 'how to resolve unfinished business'. The Personal Needs Involving Others sub-category includes need statements relating to client understanding and appreciating the family caregiver.

Formal support system. Some patterns were identified when the needs within a need sub-category were primarily being met by the formal support system. The separate support categories always included either a doctor and nurse or just a nurse and in every case it is preferred that they provide more support. It was preferred that Home Care provided the same or more support than it was in all but the sub-category of Financial Psychological Needs. In this sub-category the family caregivers want

Home Care to do less and a community organization, primarily the government, to do more. In all three sub-categories involving needs relating to the household, it is preferred that the formal support system provide more support.

Informal support system. In those sub-categories where the informal support system is meeting the needs there are two noteworthy findings. It is generally preferred that friends and family provide more support, except in the sub-category of Extra Client Care Needs. Any time the client is stated as helping to meet needs, it is preferred that they provide the same amount of support or less, except in the sub-categories of Psychological Needs Involving Others and Personal Needs Involving Others. In both of these sub-categories there are needs which must involve clients directly, such as 'understanding from family member' and 'ways to talk with family member'.

Match between preferred and existing sources of support. In some need sub-categories, the frequency that a support category is helping to meet needs is the same as the frequency that they are preferred to meet the needs. In both of the sub-categories involving spiritual needs, the support categories who are meeting the needs are the ones who are preferred to meet the needs. In the sub-categories of Information Involving Others and Client Care Needs Regarding Comfort, the spouse is providing as much support as is preferred. Within the sub-category of General Information, the nurse is providing as much support as family caregivers prefer. Counsellors and Social Workers are providing the amount of preferred support in the sub-category of Personal Household Needs. In the sub-category of Client Care Needs Regarding Food and

Nutrition, all of the respondents except for the nurse are preferred not to change. The nurse is preferred to provide more support in this area. Home Care is providing the correct amount of support in the sub-category of Client Care Needs Requiring Direct Help. Finally, in the sub-category of Psychological Needs Regarding Information it is preferred that the family continue to provide support at the current level.

Chapter Summary

The results from the research study are discussed in this chapter. Through the data presented, a description of the family caregivers in this study was obtained, their levels of depression measured, what their most and least important needs were, how well those needs were being met, who is helping to meet the needs and who the family caregivers preferred to help meet the needs. The next chapter will provide a discussion about the relevance of the study findings.

Chapter Five

Discussion

In this chapter of the thesis, the importance and relevance of the study findings will be discussed. They will be considered in relation to what is already known about the needs of home-based family caregivers of people with advanced cancer.

Demographic data

The family caregivers that took part in the study were quite similar to the known population characteristics. All but two of the family caregivers were female, which is in line with previous descriptions of family caregivers (Given & Given, 1996; Laizner, et al, 1993). Given and Given (1996) also suggest that the majority of family caregivers are wives caring for husbands and daughters caring for parents. Seven of the ten caregivers fit these categories. It is known that the majority of family caregivers actually live with their ill loved one (Given & Given, 1996), as is the case with eight of the caregivers in this study. The caregivers in this study also spent a great deal of time providing care to their loved ones. Only one caregiver in this study spent less than 30 hours providing care, which agrees with the approximately 35 hours a week that was determined by Given, Given, & Stommel (1994).

There were two areas where the demographic findings in this study did not agree with those in previous research. The first finding is that the average age of the caregivers in this study was 57.5 years; less than the 61 years cited in Laizner, et al., 1993). However, this mean may have been artificially lowered because of the young

daughter who participated in the study. The mean caregiver age would be 60.5 if she is excluded from the calculation. The second discrepancy was that none of the family caregivers in this study had to change work status as a result of their caregiving role. This is in direct contrast to literature that states that family caregivers usually must adapt their work situations, for example work less or take leaves of absence, in order to provide care (Neal, Chapman, Ingersol-Dayton, & Emlen, 1993). A possible reason for this difference is that six of the caregivers in this study were already retired or did not work. Of the other four caregivers, one worked part-time, one provided five hours of care per week, one had a spouse who stayed at home, and the last one provided care at night, after work, and on weekends. It is also possible that these results are unique to this particular sample.

Depression

Research has been conducted in the area of depression in family caregivers of cancer patients (Given, Stommel, Given, Osuch, Kurtz & Kurtz, 1993; Kurtz, Kurtz, Given & Given, 1995; Miaskowski, Kragness, Dibble & Wallhagen, 1997) which would lead one to expect depression to be a problem for the family caregivers in this study. Yet this was not the case with the caregivers in this study who only rated as mildly or moderately depressed according to the standard BDI-II rating criteria. In fact, if a minimal depression cut-off score of 17 is used instead of 13 to minimize the number of false positive scores (Beck, Steer & Brown, 1996), then none of the family caregivers in this study would be considered more than minimally depressed. In order

to explain this unexpected finding it is important to understand a problem that arises when attempts are made to measure depression. There is no one clearly defined definition of depression (Pasacreta, 1997). People loosely use the term depression to describe anything ranging from clinical depression as a result of biochemical imbalances to feeling 'blue'. One family caregiver who had previously experienced a clinical depression clearly differentiated the depression previously experienced with the depression that was experienced as a result of caregiving. Any depressive symptoms that this family caregiver identified were as a direct response to caring for and eventually losing a spouse. For example, changes in sleep patterns, increased fatigue and difficulty in concentration occurred because the ill loved one needed care frequently during the night. Increased sadness and crying were directly related to grief at the prospect of losing a loved one to cancer. All of the family caregivers experienced a lowering of mood, but these occurred as a result of caregiving demands and the grief process and was not the type of depression that is measured using the BDI-II. It is important to realize that this lowering of mood can significantly affect family caregivers, though, considering that one of the three least satisfied needs of family caregivers was 'ways to deal with depression'.

Health care needs

The sub-scale of needs which the family caregivers considered to be the most important in this study was PERSONAL NEEDS. It was also their most satisfied need sub-scale. It is an area where the family caregivers can and do meet a great number of

the needs for themselves. Yet it has the second highest BNS, which indicates that support for meeting their own personal needs is still an important consideration. Meeting one's own personal needs requires time. These findings suggest that when caregivers must choose between meeting their own personal needs and the needs of their ill family member, their own needs lose out.

The sub-scale of PSYCHOLOGICAL NEEDS was considered by the family caregivers to be the least important and also the least satisfied. This is interesting because most other studies using the HCNS indicate that this is the most important need sub-scale (Hileman & Lackey, 1990; Wingate & Lackey, 1989; Hileman, Lackey & Hassanein, 1992; Harrington, Lackey & Gates, 1996). It is possible that, because the family caregivers consider their psychological needs to be of least importance, they make little effort to get these needs met. They focus their energy and attention, instead, on the client's needs. Perhaps they even avoid dealing with their own psychological needs. They may suppress their emotions and ignore disturbing thoughts such as death and funeral planning. Another potential reason why their psychological needs are not being met is that no one may be able to help them meet the needs.

The NEEDS INVOLVING INFORMATION SUB-SCALE was considered to be the second most important need sub-scale and the third well satisfied sub-scale. Yet it has the highest BNS. Obviously, greater effort must be made to support family caregivers in this area.

The three need statements which were considered to be the most important to the family caregivers; 'information about how to give medications', 'information about the

type and extent of disease', and 'equipment for client care'; were all expected to be met by the formal support system. The formal support system was also the preferred agent to meet the needs in two of the three most important need sub-categories, Information About the Client and Disease and Direct Help with Client Care. The two need statements relating to children did not apply to any of the caregivers because none of them had children in the home.

One need which was least well satisfied, 'time for self away from the house', highlighted the need for respite. In a qualitative study by Strang (1995), family caregivers of dementia clients defined respite as a mental state where they were "free from the worries, responsibilities, and hassles of being a caregiver" (p. 173). These caregivers differentiated between a break from caregiving responsibilities and respite. Short breaks would allow time for chores and errands, but might not be long enough or of an adequate quality to constitute a respite experience.

Support roles

Family caregivers want the formal support system to help them meet their needs. The areas where they can best help is by providing factual information and by helping to care for the client. These findings are consistent with previous literature (Lewandowski & Jones, 1988; Welch, 1981). Another sub-category where the formal support system was preferred to participate was with Personal household needs, such as providing a caregiver hotline and providing respite. The family caregivers also want more help from the formal support system in the area of Practical household needs.

The informal support system was also helping to meet family caregiver needs. They were preferred to meet needs such as 'continuing my social activities', 'providing support' and being 'someone to talk to'. In fact, 'someone to talk to' was one of the best satisfied needs according to the family caregivers. They were also valuable to help meet spiritual and psychological needs. The informal support system was preferred to help meet the family caregivers emotional needs and helped out in the area of Practical Household Needs.

The family caregivers, themselves, want to meet a great number of the needs themselves. Although they expect to help meet the majority of the needs, in general they would prefer to receive more support than they were receiving.

Family caregivers' desire for increased support from the client, particularly in the areas of understanding and appreciation, is noteworthy. Two studies help to explain this finding (Douglass, 1997; Wright & Aquilino, 1998). Douglass (1997) discovered the importance of "reciprocal support" between caregivers and their spouses with cancer. When reciprocal support decreased, caregivers' feelings of self esteem decreased and levels of depression increased. In a study by Wright and Aquilino (1998), it was found that a high level of "emotional support exchange" between caregiving wives and their husbands decreased caregiver burden and increased marital satisfaction. These studies suggest that provision of emotional support is an important contribution which the client is expected to make, despite being ill.

One other interesting finding involves support from other health care professionals. The most commonly identified professional, other than a doctor or a nurse, was a

Pharmacist. Social Workers, Counsellors and Dieticians were rarely mentioned. No other health care professionals were identified. Considering the importance of the multidisciplinary team in community health care and in pallitive care, particularly, this was a disappointing finding. One potential reason for this result may be that family caregivers do not recognize the potentially valuable contributions of these other health care professionals in providing formal support. Also, family caregivers occasionally stated that home care helped to meet their needs and may have considered these other professionals to be included in that classification. It is also possible that the family caregivers who took part in the study did not come into contact with these other health care professionals.

The range of people, including themselves and their ill family members, that the family caregivers identified as helping to meet their needs is significant. It shows that caregivers are versatile, resourceful and practical when it comes to getting their needs met. They will access a wide range of formal and informal supports, depending on the need. They also know which support system would likely be the best source of the assistance required.

Chapter Six

Summary and Conclusion

Summary

In this thesis, a descriptive pilot study of the support needs of family caregivers of home-based patients with advanced cancer was discussed. A literature review identified what is already known about the characteristics of home-based family caregivers, what their support needs are, how well their needs are being met, the effects of unmet needs on family caregivers, who is currently meeting the needs and who the family caregivers would prefer to meet the needs. It was discovered that little is known about which support system is meeting which family caregiver needs. Also, who the caregivers would prefer to meet their needs was identified. An adaptation of the Home Caregiver Need Survey, the Beck Depression Inventory II, and a demographic form was used to gather information from ten family caregivers. Information was sought about the characteristics of the caregivers, what their support needs were, how well these needs were being met, which support system was meeting which need and which support system was preferred to meet the needs. Also, because this was a pilot study, information about the feasibility of the research protocol was required to facilitate a future large scale study.

The family caregivers in this group identified many support needs. They identified their most important needs as personal and their least important needs as psychological. Their most satisfied and least satisfied needs were also personal and psychological,

respectively. It was discovered that they want to meet the majority of those needs themselves, but require help. If the family caregiver support need involves information or help with care of their ill loved one they prefer that the formal support system help to meet those needs. The informal support system was preferred to help meet personal, spiritual, psychological and emotional needs that the family caregivers themselves were not able to meet. The family caregivers were versatile when it came to getting their needs met. They would seek help from as many different sources as they could to get the need met as well as possible.

Implications for nursing

This study clearly reinforces what the literature says is the nurse's role when providing support for family caregivers of home-based clients with advanced cancer. We are to provide as much information as possible, and take the best possible care of the client. According to these family caregivers, their psychological and emotional needs are best met by the caregivers themselves with help from the informal support system. These findings suggest that instead of nurses attempting to meet the psychological and emotional needs of family caregivers, our time and effort would best be spent trying to facilitate the informal support system to meet those needs and provide opportunities for caregiver respite.

Implications for future research

The results of this descriptive pilot study cannot be generalized to the population of home-based family caregivers of clients with advanced cancer. Therefore, this study needs to be repeated with a larger sample size. We now have a beginning knowledge of the family caregiver's preferences for formal and informal support system roles. Much more information is required in this area, particularly about the roles of the informal support system in this population.

There are a few changes that would be recommended for future research if the same research protocol was to be used. The BDI-II did not measure the concept of depression well in this population. If depression is to be studied, perhaps another method of measurement would be more helpful. The HCNS is very long and needs to be shortened to make it easier to use. The method used to recruit a study sample resulted in a slow accrual of participants. In future, more sources of study participants need to be used and special emphasis placed on gaining the support of any gatekeepers that may be present within those sources.

Conclusion

This study suggests that family caregivers are resourceful and self-reliant. They have a clear understanding of their needs and who might best meet those needs. They demonstrate a realistic view of the role of the formal health care system and of their informal support system. With regards to the informal system, they have clear and realistic expectations of themselves and of their loved one - the client. This study

needs to be replicated with a larger population pending changes to the measure of caregiver needs.

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Appendix A

Home Caregiver Need Survey (Adapted)

(HCNS)

HOME CAREGIVER NEED SURVEY

Directions:

The following list of needs was identified by caregivers of family members at home. To identify your needs as a caregiver of a family member at home, please:

1. Read the first need statement.
2. If the statement does not apply to you check the box under "DOES NOT APPLY TO ME".
3. If the statement does apply to you,

PLEASE EVALUATE EACH NEED STATEMENT IN FOUR WAYS:

First, ask yourself **"How important is this need for me?"** Then beside that need statement, please check a box between "very important" and "not important" to show how important that need is for you.

Second, ask yourself **"How satisfied is this need for me?"** Then please check one box between "not satisfied" and "very satisfied" to show how satisfied that need is for you.

Third, ask yourself **"Who, in whole or part, is meeting this need for me?"** Then please list the category(s) of people who are meeting that need for you. Examples of possible categories are: Physician, nurse, paraprofessional, aide, spouse, son/daughter, family, friend, neighbour, and spiritual leaders.

Fourth, ask yourself **"Who would I prefer to meet this need for me?"** Then please list the category(s) of people who you would prefer to meet that need for you.

Follow this procedure for each item. Don't spend too much time on your answers; your first thought is probably the best. Please answer every statement and be sure to mark **two boxes** and make **two lists** for each statement that applies to you.

EXAMPLE:

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box		HOW SATISFIED IS THIS NEED FOR YOU? Please check a box		WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
		Not Important	Very Important	Not Important	Very Important		
1. Support from my neighbors.	☐	☐☐☐☐☐☐☑		☑☐☐☐☐☐☐		*none*	*neighbor*

This example would indicate a need which was very important, but not satisfied, and neighbors are preferred to meet the need.

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box		HOW SATISFIED IS THIS NEED FOR YOU? Please check a box		WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
		Not Important	Very Important	Not Important	Very Important		
I. NEEDS INVOLVING INFORMATION							
1. Information about medications – effects and schedules	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
2. Information about treatment side effects	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
3. Information about the underlying reasons for symptoms	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
4. Information about what symptoms to expect	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
5. Access to physicians	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
6. Honest and updated information	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
7. Information about the physical needs of my family member	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
8. Information about therapies	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
9. Information about drugs	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
10. A trusting relationship with my family member	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
11. Information about the type & extent of my family member's disease	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
12. Information on how to give medications	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
13. Ways to inform children	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
14. Ways to cope with role changes	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box: Not Important	Very Important	HOW SATISFIED IS THIS NEED FOR YOU? Please check a box: Not Important	Very Important	WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
II. NEEDS INVOLVING YOUR HOUSEHOLD							
1. Help with errands	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
2. Help with my housework	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
3. Help with transportation	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
4. Help with my yard work	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
5. A caregiver hotline	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
6. Non-professional help with my family member's physical care	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
7. Time for myself – away from the house	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
8. Help continuing my children's activities	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
9. A caregiver support group for me	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
10. Places to go for professional counseling	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
11. Help with baby sitting	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
12. Information about community resources	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
II. PATIENT CARE NEEDS							
1. Ways to help my family member maintain some independence	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box Not Important	Very Important	HOW SATISFIED IS THIS NEED FOR YOU? Please check a box Not Important	Very Important	WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
2. Ways to keep my family member comfortable	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
3. Information about which liquids are best for my family member	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
4. Ways to provide my family member with adequate nutrition	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
5. Methods of pain control	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
6. Activities that will make my family member feel purposeful	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
7. Ways to deal with my family member's decreased energy	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
8. Information about how to get my family member to eat	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
9. Ways to dress my family member comfortably	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
10. Equipment to help with family member care	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
11. Ways to reassure my family member	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
12. Professional help with my family member's physical care	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
13. Ways to improve my family member's appearance	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
14. Ways of coping with my family member's diagnosis	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box Not Important	Very Important	HOW SATISFIED IS THIS NEED FOR YOU? Please check a box Not Important	Very Important	WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
15. Not leaving my family member alone	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
16. Home visits by professionals to check my family member	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
IV. PERSONAL NEEDS							
1. Time for my personal needs	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
2. Time to rest	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
3. Maintaining my own health	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
4. Adequate sleep	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
5. Someone with whom to talk	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
6. Understanding from my family member	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
7. Appreciation from my family member	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
8. Continuing my social activities	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
9. Support from my family	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
10. Support from my friends	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
11. Caring and interested professionals	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
VI. PSYCHOLOGICAL NEEDS							
1. Ways to deal with the unpredictability of the future	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____
2. Information about death and dying	☐	☐☐☐☐☐☐☐		☐☐☐☐☐☐☐		_____	_____

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box		HOW SATISFIED IS THIS NEED FOR YOU? Please check a box		WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
		Not Important	Very Important	Not Important	Very Important		
3. Help dealing with my fears	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
4. Ways to deal with my depression	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
5. Ways to discuss death with my family member	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
6. Information about what to expect in the future	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
7. Ways to deal with my anger	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
8. Information about funeral planning	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
9. Ways to deal with my guilt feelings	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
10. Information on hospice care	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
11. Information about legal matters	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
12. Ways to be more patient and tolerant	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
13. Ways to resolve unfinished business with my family member	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
14. Ways to maintain a normal family life	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
15. Help with financial matters	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
16. Ways to better communicate with my family member	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
17. Ways of coping with my loneliness	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
18. Ways to combat fatigue	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
19. Methods to decrease my stress	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____
20. Ways to encourage my family member	☐	☐☐☐☐☐☐		☐☐☐☐☐☐		_____	_____

	DOES NOT APPLY TO ME	HOW IMPORTANT IS THIS NEED FOR YOU? Please check a box Not Important → Very Important	HOW SATISFIED IS THIS NEED FOR YOU? Please check a box Not Important → Very Important	WHO IS MEETING THIS NEED FOR YOU?	WHO WOULD YOU PREFER TO MEET THIS NEED?
21. Feedback that I am giving my family member proper care	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
22. Bereavement follow up	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
23. Ways to inform family	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
24. Information about my family member's psychological needs	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
25. Classes on giving physical care to my family member	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
26. A patient support group for my family member	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
27. Financial help	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
28. Ways to deal with my sexual needs	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
29. Information about activities and exercises for my family member	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
30. Help with understanding insurance forms	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
_____	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
_____	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____
_____	☐	☐☐☐☐☐☐☐	☐☐☐☐☐☐☐	_____	_____

Appendix B

The Beck Depression Inventory, 2nd edition (BDI-II) has been removed because of copyright restrictions. This material can be obtained from The Psychological Corporation, 55 Horner Avenue, Toronto, Ontario. M8Z 4X6

Appendix C

Demographic Information Sheet

Caregiver Information

Marital Status: Married __ Widowed __ Divorced __
Common-Law __ Never Married __

Age: __ years

Gender: Male __ Female __

Education: Grade 8 or less __ Some High School __ High School Diploma _
Post-secondary Education __ Graduate Education __

Occupation: Clerical __ Homemaker __ Laborer __ Management __
Professional __ Retired __ Other (please specify) _____

Employment Status: F. T. __ P. T. __ Casual __ Unemployed __
Has your employment status changed since you have become a caregiver?
Yes __ No __ If yes, please describe the change _____

Relationship to Patient: Spouse __ Son __ Daughter __
Other (please specify) _____

Do you live with the patient? Yes __ No __

Income: Below $10,000/year __ $10,000-20,000/year __
$21,000-30,000/year __ $31,000-40,000/year __
$41,000- 50,000/year _ Over $50,000/year __

Ethnic Background: _____

Religion: _____

How many hours/week do you provide care for the patient?
1-5 hrs __ 6-10 hrs __ 11-15 hrs __ 16-20 hrs __
21-25 hrs __ 26-30 hrs __ Over 30 hrs __

Patient's Diagnosis: _____

Patient's Age: __ years

Patient's Gender: Male __ Female __

Date of Diagnosis: _____

Appendix D

Ethical Clearance Letters

Home Caregiver Need Survey (HCNS)

Beck Depression Inventory, 2nd Edition (BDI-II)

University of Alberta Ethical Review Board

Capital Health Authority

Lakeland Reginal Health Authority

Capital Health Authority- Home Care

Pilgrims Hospice Society

School of Nursing

University of Missouri-Kansas City
2220 Holmes Street
Kansas City, Missouri 64108-2676

UMKC

August 9, 1995

Jo-Anne Pollard
Clinical Sciences Building, Room 3-120
University of Alberta
Edmonton, Alberta
Canada, T6G 2G3

Office of the Dean
816 235-1700
Academic Programs
816 235-1769
Advancement Office
816 235-1775
Business Office
816 235-1732
Distance Education
816 235-1710
Student Services
816 235-1740
Fax
816 235-1701

Outreach Sites:
Joplin, MO
417 625-9322
St. Joseph, MO
816 271-5914

Dear Jo-Anne,

It was great hearing from you! Good luck on your master's research! We have come up with a generic copy of the Home Caregiver Need Survey (HCNS) since the article you referred to in your letter. Enclosed you will find a "generisized" copy of the Home Caregiver Need Survey. Five one-word changes were made so the instrument could be used with caregivers of any population at home. I have used it with caregivers of patients with AIDS and got high reliability and validity (see abstracts enclosed).

Enclosed you will find a couple copies of the HCNS and a copy of the articles I've published (except for the one you have). The instrument development and the AIDS study have been published yet. I also enclosed some abstracts that will give you reliability and validity information.

You have my permission to use the tool or any part of it. I'm getting ready to do a study and just use the three sections on Psychological, Informational, and Patient Care. Each section (sub-scale) has it's own reliability. I haven't worked on each item (in depth).

Many hospices are using my instrument upon admission to hospice services. It works really well for a one-on-one (nurse and family caregiver) because you can eye-ball it and if you see 2 "X's" close together, it indicates a need that is both important and not satisfied. Interventions to meet these caregiver needs is then built into the care plan. Then the nurses take additional copies of the HCNS and highlight the need items that that were important and not satsfied for this caregiver and in succeeding visit, the nurse checks to see if they are making progress on meeting the caregiver's unmet needs.

Let me know if I can be of further help. Call me anytime: H 913-432-6325, W 816-235-1720. Good luck!

Sincerely,

Judy Hileman

Judy Willis Hileman, ARNP, PhD
Assistant Professor, Coordinator Distance Education
UMKC School of Nursing

an equal opportunity institution

THE PSYCHOLOGICAL CORPORATION®

The Psychological Corporation
55 Horner Avenue
Toronto, ON
M8Z 4X6
TEL: (416) 255-4491
FAX: (416) 255-4046

September 21, 1998

Ms. Jo-Anne Pollard, MN Candidate
Faculty of Nursing
3rd Floor, Clinical Sciences Building
University of Alberta
Edmonton, Alberta
T6G 2M7

Dear Ms. Pollard:

Thank you for your letter of August 14, 1998. As per our recent telephone conversation, we can not grant permission for the inclusion or appending of any of our tests in theses or dissertations where they are available to the general public on an unsupervised basis. Therefore, we can not grant permission to include a copy of any BDI-II items that you used for your research in the bound thesis.

However, you are already registered to use the BDI-II. Should you have any questions regarding permissions issues, please contact our Legal Services Department at 1-800-211-8378. Thank you.

Sincerely,

Deborah Davidson
Projects and Marketing Coordinator

University of Alberta
Edmonton
Canada T6G 2G3

Faculty of Nursing
3rd Floor Clinical Sciences Building

Certification of Ethical Acceptability for Research Involving Human Subjects

---

NAME OF APPLICANT(S): Joanne Pollard, MN Candidate

TITLE OF PROJECT: "Formal and Informal Fullment of the Support Needs of Family Caregivers with Palliative Cancer Patients at Home"

The members of the review committee, having examined the application for the above named project, consider the procedures, as outlined by the applicants, to be acceptable on ethical grounds for research involving human subjects.

11 Jan 97
Date

Beverley O'Brien, PhD
Chair, Ethics Review Committee

ERC 96-106
5005-02-106

Capital Health Authority

Regional Research Administration Office
WMC 5C2.16, 492-1372

Memorandum

NOTICE OF APPROVAL FOR PROPOSED RESEARCH
UNIVERSITY HOSPITALS SITE

Project Title:	Formal and Informal Fullment of the support Needs of Family Caregivers with Palliative Cancer Patients at Home
Project No.:	P-15
Investigator(s):	Jo-Anne Pollard
Department:	Faculty of Nursing
Division:	-
Address:	CSB 3-314
Phone/FAX:	488-6730

Supporting documents:

1)	Ethical Approval	January 1997
2)	Study Protocol	Received
3)	Funds:a) Source	Edna Minton Endowment for Cancer Nursing Research Student Bursary
	b) Type	Grant
4)	Overhead Negotiated	N/A
5)	Account #	Unknown
6)	Contract	N/A

Project Approved March 1997

THIS APPROVAL IS VALID FOR ONE YEAR

By

Title

Barbara Brady-Fryer
Regional Manager
Research Administration
Capital Health Authority

Copies to: Department Chair/Health Sciences Faculty
Finance

March 19, 1997

LAKELAND Regional Health Authority

Vegreville Health Unit
Box 99, 5318 - 50 Street
Vegreville, Alberta T9C 1R1
Telephone: (403) 632-3331
Fax: (403) 632-4334

May 27, 1997

Ms Jo-Anne Pollard
#229 - 10160 - 114 St.
Edmonton AB T5K 2L2

Dear Jo-Anne,

Re: Formal and Informal Fulfillment of the Support Needs of Family Caregivers with Palliative Cancer Patients at Home

I am pleased to confirm in writing Lakeland Regional Health Authority's support for your research project. We believe your research can provide us with feedback on the needs of informal caregivers, how well the needs are being met and some insight in adjusting our services to caregivers.

On behalf of the Community Care Supervisors, thank you for attending our meeting on April 25 in St Paul. I would like to reiterate the invitation to call the supervisors directly if you require information specific to their caseloads or geographical areas. The supervisors may be contacted as follows:

Area 1 - Donalda Mauthe Jakeman	ph. 632-3331 fax 632-4334
Area 2 - Gladys Bellerive	ph. 645-3396 fax 645-6609
Area 3 (Cold Lake) Diane Labossiere	ph. 594-4404 fax 594-2404
(Lac La Biche) Jean Welke	ph. 623-4471 fax 623-2615

I would like to request a copy of your research paper when it is ready be released. If I can be of further assistance feel free to call me at 632-3331 or by fax at 632-4334.

Sincerely

Jane Trabysh

Jane Trabysh
Regional Community Care Coordinator

cc B. Bell
Dr. N. Bayliss
M. James
P. Babiuk
D. M. Jakeman
G Bellerive
D. Labossiere
J. Welke

jt

Capital Health Authority

FILE COPY
COMMUNITY HEALTH
Home Care

June 19, 1997

Barbara Brady-Fryer
Regional Manager, Research Administration
Capital Health Authority
5C2.16 Walter MacKenzie Centre
71A University Campus
EDMONTON, Alberta
T6G 2E1

Dear Ms. Brady-Fryer:

I have received the research proposal "Formal and Informal Fulfillment of the Support Needs of Family Caregivers with Palliative Cancer Patients at Home" by Joanne Pollard and support undertaking this research in our program once appropriate ethics review has been obtained.

Sincerely,

Gloria Mohr
Director, Home Care
Capital Health

GM/aik
cc: Joanne Pollard

Misericordia Community Health Centre
8th Floor, 16940 - 87 Avenue
Edmonton, Alberta
Canada T5R 4H5

Tel: (403) 486-8445
Fax: (403) 944-4424

July 24, 1997

Jo-Anne Pollard
3-132 Clinical Sciences Building
University of Alberta

Dear Jo-Anne:

Your research proposal " Formal and Informal Fullment of the Support Needs of Family Caregivers with Palliative Cancer Patients at Home" has been reviewed by three members of our Board. We concluded that your proposal appears to be a sound research project and has the potential to provide valuable insights into the issues surrounding family caregivers. Pilgrim's Hospice Society would be pleased to co-operate in terms of allowing you to access our clients for your data collection. Terri Fortunaso, Day Program Manager, will be your agency contact person.

We look forward to working with you and will be very interested in your findings.

Sincerely,

Gloria Bauer,
Chair, Board of Directors

Pilgrims Hospice Society
600 Riverbend Square
Edmonton, AB T6R 2E3
Ph: (403) 413-9801
Fax: (403) 988-8903

Appendix E

Information Letters

Information Letter (Client)

Dear ,

I am a Registered Nurse in the Master of Nursing program at the University of Alberta. This letter is being written to provide information about a research study which I am doing and to ask you to consider taking part in it. The purpose of the research study is to discover what caregivers need to help them take care of their ill family members, who is meeting those needs, and who would be preferred to meet those needs. The information gained through this study could help nurses: 1) learn what family members need to help them in their caregiving roles, 2) focus their efforts on helping family members with what they feel are important needs, and 3) learn about the role of friends and other family members in helping family caregivers. Family members do not necessarily need to be related by blood or marriage; very close friends may also be considered family.

If you agree to participate in the study, you will be asked to identify a family member who helps to take care of you. Your involvement should only take a few minutes. This person will be contacted by mail to see if they would like to participate in the study. Any information which could be used to identify you or your family member will be kept confidential. I will be the only one who has access to it. If you do not want to participate in the study or if you want more information, please contact me at 488-6730. If I do not hear from you in two weeks, I will contact you about participating in the study. I appreciate your interest and any help you can provide.

Sincerely,

Jo-Anne Pollard

Information Letter (Family Caregiver)

Dear ,

I am a Registered Nurse in the Master of Nursing program at the University of Alberta. This letter is being written to provide information about a research study which I am doing and to ask you to consider taking part in it. The purpose of the research study is to discover what caregivers need to help them take care of their ill family members, who is meeting those needs, and who would be preferred to meet those needs. The information gained through this study could help nurses: 1) learn what family members need to help them in their caregiving roles, 2) focus their efforts on helping family members with what they feel are important needs, and 3) learn about the role of friends and other family members in helping family caregivers. Family members do not necessarily need to be related by blood or marriage; very close friends may also be considered family.

_____ has identified you as a family caregiver. If you agree to participate in the study, you will be asked to complete three information forms asking you about yourself, your ill family member, and what you need to help provide care for your family member. This should take you about 1 1/2 hours. Any information which could be used to identify you or your family member will be kept confidential. I will be the only one who has access to it. If you do not want to participate in the study or if you want more information, please contact me at 488-6730. If I do not hear from you in two weeks, I will contact you about participating in the study. I appreciate your interest and any help you can provide.

Sincerely,

Jo-Anne Pollard

Appendix F

Consent Form

CONSENT FORM

Title of research study - Formal and informal fulfillment of the support needs of family caregivers with palliative cancer patients at home.

The purpose of this study is to determine the support needs of family caregivers of advanced cancer patients in the home and to determine family caregiver's preferences for who might best meet those needs.

Taking part in this study involves filling out three forms. It will take about 1 1/2 hours to complete the forms. The researcher will stay in the room to answer any questions which you may have and will personally assist you with one of the forms.

There is no direct harm or benefit to you because of taking part in the study. However, the information learned from the study may help future family caregivers.

You do not have to take part in this study. If you do decide to take part, you can withdraw at any time simply by telling the researcher your wishes. Also, you do not have to answer any questions that you do not want to answer. Whether or not you take part in the study will have no effect on the current health care that your family member is receiving.

The researcher is the only person who has access to any information which could be used to identify you or your family member. Numbers instead of names will be used on the information sheets as further protection. Also, no information that could be used to identify you will be included in reports or presentations about the study. The information forms will be kept for future research, with ethical review, but all information which could be used to determine your identity will be destroyed after the study is complete. If you have any questions, you can contact the researcher, Jo-Anne Pollard, or her thesis supervisor, Dr. Ross Kerr, at any time.

Jo-Anne Pollard
Master of Nursing Candidate
Faculty of Nursing
University of Alberta
488-6730

Dr. J. Ross Kerr
Thesis Supervisor
Faculty of Nursing
University of Alberta
492-6253

I, _____ , have read this consent form and agree to take part in the study titled "Formal and informal fulfillment of the support needs of family caregivers with palliative cancer patients at home." The study has been explained to me and all of my questions have been answered by the researcher. I have been given a copy of this consent form.

_____ _____
Signature of participant Date

_____ _____
Signature of Researcher Date

If you wish to receive a summary of the study results, mark an X in the space provided. _

Appendix G

Need Sub-categories

Need Sub-categories

1) NEEDS INVOLVING INFORMATION
- a) Information re: Medications and Treatments
  - Information re: medication effects and schedules
  - Information re: treatment side effects
  - Information re: therapies
  - Information re: drugs
  - Information re: how to give medications
- b) Information re: Client and Disease
  - Information re: reasons for symptoms
  - Information re: symptoms to expect
  - Information re: client's physical needs
  - Information re: type and extent of disease
- c) Information Involving Others
  - Trusting relationship with client
  - Ways to tell children
  - Ways to cope with role changes
- d) General Information
  - Access to doctors
  - Honest, updated information

2) NEEDS INVOLVING YOUR HOUSEHOLD
- a) Practical Needs
  - Help with errands
  - Help with housework
  - Help with transportation
  - Help with yard work
  - Non-professional help with client's physical care
  - Help continuing children's activities
  - Help with babysitting
  - Information re: community resources
- b) Personal Needs
  - Caregiver hotline
  - Time for self away from house
  - Caregiver support groups
  - Places for professional counseling

3) CLIENT CARE NEEDS

a) Food and Nutrition
- Information re: best liquids
- Ways to provide adequate nutrition
- Information re: client eating

b) Comfort
- Ways to keep client comfortable
- Methods of pain control
- Ways to dress client

c) Direct Help
- Equipment for client care
- Professional help for client care
- Not leaving client alone
- Home visits by professionals

d) Psychosocial
- Ways to help client with independence
- Activities to make client feel purposeful
- Ways to reassure client
- Ways of coping with diagnosis

e) Extra
- Ways to deal with client's decreased energy
- Ways to improve client appearance

4) PERSONAL NEEDS

a) Independent Personal Needs
- Time for personal needs
- Time to rest
- Maintaining own health
- Adequate sleep

b) Personal Needs Involving Others
- Someone to talk to
- Understanding from client
- Appreciation from client
- Continuing my social activities
- Support from my family
- Support from my friends
- Caring and interested professionals

5) SPIRITUAL NEEDS

a) Personal Spiritual Needs

Personal prayer for strength
Strong faith in a Supreme Being
Hope for future

b) Spiritual Needs Involving Others

Prayers from others
Support from my place of worship
Spiritual leaders to talk to

6) PSYCHOLOGICAL NEEDS

a) Emotional

Ways to deal with the future
Ways to deal with fear
Ways to deal with depression
Ways to deal with anger
Ways to deal with guilt
Ways to be more patient and tolerant
Ways of coping with loneliness
Ways to decrease stress
Bereavement follow-up
Ways to deal with sexual needs

b) Information

Information re: death and dying
Information re: what to expect in the future
Information re: funeral planning
Information re: hospice
Information re: legal matters
Ways to combat fatigue
Feedback re: proper care of client
Information re: client's psychological needs
Classes re: client's physical care
Information re: activities and exercizes
Help re: insurance forms

c) Psychological Needs Involving Others

Ways to discuss death with client
ways to resolve unfinished business
Ways to maintain family life
Ways to talk with client
Ways to encourage client

Ways to tell family
Support group for client

d) Financial
Help with money
Financial help